



Scottish Women's Convention response to the Scottish Government's: Draft Framework for Pain Management Service Delivery

February 2022

Premise

The Scottish Government are committed to improving care for people with chronic pain. In support of this, they made a number of commitments in their Programme for Government, including the development of a new Framework for Pain Management Service Delivery.

This draft Framework sets out a vision of providing person-centred, effective and safe care that improves the quality of life and wellbeing of people living with chronic pain in Scotland, and describes their commitments to deliver this ambition.

This consultation invites people living with chronic pain, those who provide pain management services and support, and wider health, social care and third-sector organisations to consider and respond to the commitments made in the draft framework.

The Scottish Women's Convention (SWC)

The Scottish Women's Convention (SWC) is funded to engage with women throughout Scotland in order that their views might influence public policy. The SWC uses the views of women to respond to a variety of parliamentary, governmental, and organisational consultation papers at both a Scottish and UK level.

The SWC engages with women using a range of methods, including roadshow events, thematic conferences, and regional contact groups. This submission provides the views of women, reflecting their opinions and experiences in key areas relevant to women's equality.

The SWC is currently engaging with women through digital roadshows, online surveys, asking women to comment by email, and by telephoning those who want to talk. We are also using our wide network to ask women to collate views in their local communities and forward these to us on a regular basis. We are continuing to review innovative ways of engaging with women throughout Scotland using whichever medium is appropriate to them.

Vision

1. Should this be the overarching vision?

"Our Vision is for person-centred, effective and safe care that improves the quality of life and wellbeing of people living with chronic pain in Scotland".

Yes

2. Please explain your answer to Q1.

The woman we spoke to agreed that this was a positive vision for the framework, but they did have some reservations about it:

- "It seems quite broad."
- "It sounds ideal but is perhaps too idealistic."
- "It is acceptable but not imaginative."
- "It sounds quite simple, however is it realistic?"

Aim A: Person-Centred Care

3. Should this aim be a priority?

PERSON-CENTRED CARE: Ensure access to appropriate information and support based on an individual's needs.

Yes

4. Should Commitment 1 be included in the Framework?

Commitment 1: We will improve the quality and consistency of information on chronic pain and make it more easily accessible. We will empower people to understand their condition and better manage its impact on their physical and mental wellbeing.

Yes

5. Please explain your response to Q3 and Q4.

Since women so frequently experience medical gaslighting by healthcare professionals, there needs to be better support to ensure their concerns are listened to and taken seriously

- "We need mental and physical health advocates because, I know myself, I find it difficult on my own when I'm going to see doctors, and my first language is English."
- "I've had several friends who have sadly passed away because they have committed suicide because they couldn't live with the pain and obviously no one listened to them when they were complaining."
- "So many times, I've been told 'it's just your age' or 'it's just your menopause'."

"Build services based on patient experience rather than being resource-led."

There needs to be better awareness of the different types of chronic pain and the practical implications of this on individuals' lives - "Separating needs for degenerative disease from those for idiopathic pain."

We need to listen to individuals' concerns rather than taking a one size fits all approach and only relying on medication as a solution – there needs to be a more holistic approach to chronic pain that respects individuals' autonomy and needs - "I would never approach a doctor about it as I know there's nothing they can do just now, but I wouldn't have trusted before anyway because all they did in the past was feed me mountains of pills."

Aim B: Timely Access to Care

6. Should this aim be a priority?

AIM B: TIMELY ACCESS TO CARE: Support people to access the care they need when they need it.

Yes

7. Should Commitment 2 be included in the Framework?

Commitment 2: We will support people to access the right care, in the right place, at the right time by working with NHS Boards to improve how they plan and deliver care for people with chronic pain. This includes increased coordination across community-based, GP and hospital services.

Yes

8. Should Commitment 3 be included in the Framework?

Commitment 3: We will improve the options people have in accessing chronic pain services, including digital technology where appropriate.

Yes

9. Please explain your response to Q6, Q7 and Q8.

Women had mixed feelings when it came to extending digital options:

- Many women have struggled to access healthcare services during the lockdown because a lot of appointment booking processes moved online.
- "Zoom is just not the same. You do not get the same feedback. You don't get the nuances of people's thoughts and words."
- "When you're dealing with so many people you can't even reach, and it's frustrating when the algorithms don't deal with the questions that you actually need answered and there's nobody to talk to."
- "You get referred round the circle, back into the web and if you don't have the digital skills, you have a problem."
- "Face-to-face contact means a lot"
- A lot of older women do not know about the services that are out there and struggle to access them.
- "I just worry about people not getting proper in-person consultations because they could be getting sent medication that could damage them further."
- "Digital poverty is still a huge barrier as is connectivity which makes it even harder for those from rural or island communities to access these services"

Many women have to constantly fight to get access to the services they need.

- “So many women suffer from things for a very long time, and yet I find it difficult to contact my GP over and over again for the same thing. You find that you become almost a bit of a problem, having to complain all the time.”
- One woman shared that she had made 16 attempts at calling before she was able to book an appointment with her GP, but she thought a lot of people would not have been as persistent - “If someone were really in a terrible state and was not that persistent, what happens to them? I don’t know.”
- Several women noted that, because they know the services are so overwhelmed, they feel guilty about asking for help and pursuing treatment.
- Even more worryingly, several women spoke about taking their health into their own hands because they did not want to be a burden to the NHS – “I am taking responsibility for my own health, and I think we’re all going to have to help ourselves because we’re not going to get the treatment from the NHS because they’re overloaded.”

The lockdown has meant that many women have not received treatment or had access to preventative measures during the lockdown and systems need to be put in place to reconcile that.

- One woman with osteoporosis has not had any medication or physiotherapy in over two years and knows there are many other women in the same situation. She is worried about how this may have shortened her life and reduced her quality of life irreversibly.
- Women with endometriosis have told us that “COVID has obviously delayed surgeries and, in our group, we have women who have been waiting for diagnostic surgery or surgery to actually remove the endometriosis for more than two years. How is that going to be managed and not just seen as elective surgery because, at the end of the day, it’s not really elective anymore?... These are the worst cases, but these cases are starting to present on a more regular basis because that preventative care isn’t being done at the moment.”

Aim C: Safe, Effective Treatments

10. Should this aim be a priority?

Ensure people have a choice of effective treatments.

Yes

11. Should Commitment 4 be included in the Framework?

Commitment 4: We will support people with chronic pain and healthcare professionals to better understand and agree effective treatment options to manage pain.

Yes

12. Should Commitment 5 be included in the Framework?

Commitment 5: We will ensure people have more consistent access to effective treatment options wherever they live in Scotland.

Yes

13. Please explain your response to Q10, Q11 and Q12.

There needs to be better understanding of the range of conditions that exist among diverse communities and investment into how these are treated and managed:

- “Glasgow is experiencing a rise in people from diverse cultures and one of the effects of this is people with different diseases... people from the West have a different version of the disease called haemophilia or thrombosis and the health service is doing a good job of taking care of those, but there is not even one unit here that takes care of people with sickle cell anaemia patients, even though there are about 400 patients in Scotland.”

Women need to be given more information and more autonomy in their treatment choices.

- “It would be helpful to be encouraged and given access to appropriate and various methods to manage chronic pain.”

Aim D: Improving Quality of Life and Wellbeing

14. Should this aim be a priority?

Invest in training, data, and research to improve care and support.

Yes

15. Should Commitment 6 be included in the Framework?

Commitment 6: We will work with NHS Education for Scotland, professional bodies, and partners to improve training and education on management of chronic pain.

Yes

16. Should Commitment 7 be included in the Framework?

Commitment 7: We will establish and support health and care professional networks to share best practice in pain management at local and national levels.

Yes

17. Please explain your response to Q14, Q15 and Q16.

- “There needs to be more research into chronic pain - the only option given to my daughter right now is essentially 'find a way to live with it, it's all in your head'. This is both judgemental and unhelpful. She is in daily pain; it is crippling and real.”
- “Pain is NOT a choice, contrary to the words spoken by one member of staff at the Pain Management Service.”
- “Chronic pain should be given the priority it deserves, in terms of funding, research and staff training and development.”

Using Data to Improve Services and Support

18. Should Commitment 8 be included in the Framework?

Commitment 8: We will support Health and Social Care Partnerships to improve how pain management support is planned and delivered locally by promoting more consistent use of performance and quality data.

Yes

19. Should Commitment 9 be included in the Framework?

Commitment 9: We will work with Public Health Scotland to increase national reporting and analysis of clinical and patient experience data to improve services for people with chronic pain.

Yes

20. Please explain your response to Q18 and Q19.

- It is important that there is qualitative data and that women's lived experience is taken into consideration when planning and delivering services.
- From the women we have spoken to, we believe there is underreporting of chronic pain issues as many women are left to manage their conditions by themselves. The data cannot just take into account the views and experiences of the people who are successfully receiving care.
- Reporting has to be honest and transparent if it is to be used effectively in holding services and authorities to account, and there is some scepticism about whether this will be upheld.
- Consistency needs to be improved. Moves towards specialised centres for specific services have meant reduced local services, meaning many people in rural communities or more deprived areas cannot afford to access them.

Promoting research and best practice

21. Should Commitment 10 be included in the Framework?

Commitment 10: We will develop and agree national standards for pain management services to improve care for people with chronic pain.

Yes

22. Should Commitment 11 be included in the Framework?

Commitment 11: We will support pain research in Scotland to develop improved care and treatment options for people with chronic pain.

Yes

23. Please explain your response to Q21 and Q22.

- Any research needs to include women, as researchers and as subjects, to ensure that their experiences and perspectives are accounted for.
- Women also suggested setting up a working group of chronic pain survivors, empowering them to share ideas and support, and to signpost one another to services that have helped them.

Implementation and Impact Questions

24. Please share your views on the barriers to implementing the Framework.

The main themes from the women we spoke to were:

- Underfunding of services
- Understaffing of services

These leads to:

- Lack of time available in appointments to fully explain problems and explore treatment options
- Lack of detailed subject-specific knowledge among healthcare professionals
- Lack of research into chronic pain management

Here is what they said:

- “Medical staff don’t have access to the information and do not have time to read, understand and pass on as appropriate.”
- “Staff attitudes and research.”
- “Misdiagnoses of the causes of chronic pain due to lack of time available to practitioners.”
- “Ignorance about the highly individualised nature of idiopathic pain (fibromyalgia).”
- “Lack of resources and understanding.”

25. Please share your views on the opportunities to implementing the Framework.

- “Improved patient experience and outcomes.”
- “Opportunities will be dependent on adequate funding and on rigorous training that tests trainees' proper understanding of chronic pain and its variety of causes.”
- “Openness to listening to pain sufferers.”
- “Identify and highlight the difficulties faced by individuals on a daily basis.”

26. Are there any groups who will be directly or indirectly impacted by the Vision, Aims and Commitments that have not been identified by the Equality Impact Assessment and/or Fairer Scotland Duty exercises.

- Women are more likely to experience medical gaslighting than men and their genuine complaints about chronic pain are more likely to be ignored.
- A lot of healthcare practice is still centred around male physiology and women’s experiences of chronic pain are often belittled, misunderstood, or mistreated.
- There are many chronic pain conditions that affect women more than men including fibromyalgia, migraine and chronic tension-type headache, irritable bowel syndrome, temporomandibular disorders, and interstitial cystitis.

- There is a lack of research and support for conditions primarily affecting ethnic minority communities, such as sickle cell anaemia.
- In rural and island communities, access to effective, joined up services is a lot more difficult.
- Women with childcare or other caring responsibilities are often disadvantaged in accessing services and there needs to be better support to enable them to attend appointments.
- Accessibility of services needs to look at how people on low incomes are disadvantaged e.g., a lack of local health services in areas of high deprivation, or people not being able to afford to travel to health appointments.
- Medication for chronic pain can affect women's bodies differently to men's e.g., women developing osteoporosis as a result of other long-term medication.
- Women for whom English is not their first language need to be given extra support such as translation services but also better outreach in communities to overcome the cultural barriers that might prevent them coming forward with their concerns about chronic pain.

Conclusion

The SWC is grateful for the opportunity to respond to the Scottish Government's consultation on the Draft Framework for Pain Management Service Delivery. As an organisation, we will continue to work with women from across Scotland to gather voices and experiences relating to this topic and its effects on women's equality.

For further information, please contact

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